

Tilburg University

**Experiences of service users with a mild intellectual disability or borderline intellectual functioning with Flexible Assertive Community Treatment**

Neijmeijer, L. J.; Kuiper, C.; Kroon, H.; Didden, R.

*Published in:*

Journal of Applied Research in Intellectual Disabilities

*DOI:*

[10.1111/jar.12723](https://doi.org/10.1111/jar.12723)

*Publication date:*

2020

*Document Version*

Publisher's PDF, also known as Version of record

[Link to publication in Tilburg University Research Portal](#)

*Citation for published version (APA):*

Neijmeijer, L. J., Kuiper, C., Kroon, H., & Didden, R. (2020). Experiences of service users with a mild intellectual disability or borderline intellectual functioning with Flexible Assertive Community Treatment: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 33(5), 1005-1015. <https://doi.org/10.1111/jar.12723>

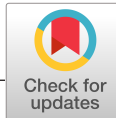
**General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

**Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.



## ORIGINAL ARTICLE

JARID

Journal of Applied Research in Intellectual Disabilities

bild

WILEY

# Experiences of service users with a mild intellectual disability or borderline intellectual functioning with Flexible Assertive Community Treatment: A qualitative study

Laura Neijmeijer<sup>1,2</sup> | Chris Kuiper<sup>3</sup> | Hans Kroon<sup>4,5</sup> | Robert Didden<sup>1,2</sup>

<sup>1</sup>Behavioural Science Institute, Radboud University Nijmegen, Nijmegen, The Netherlands

<sup>2</sup>Trajectum, Zwolle, The Netherlands

<sup>3</sup>University of Applied Sciences Leiden, Leiden, The Netherlands

<sup>4</sup>Trimbos Institute, Netherlands Institute of Mental Health and Addiction, Utrecht, The Netherlands

<sup>5</sup>Tranzo, School of Social and Behavioural Sciences, Tilburg University, Tilburg, The Netherlands

## Correspondence

Laura Neijmeijer, Behavioural Science Institute, Radboud University Nijmegen, Postbus 40012, DA Zwolle 8004, The Netherlands.  
Email: lneijmeijer@trajectum.info

## Abstract

**Background:** In the Netherlands, Flexible Assertive Community Treatment (FACT) teams have been established for people with mild intellectual disability (MID) or borderline intellectual functioning (BIF) and mental health problems or challenging behaviour. Little is known yet about service users' experiences with FACT.

**Method:** An inductive grounded theory approach was used to explore how service users valued the treatment and their own functioning, and which factors were perceived as supportive. Semi-structured interviews were held with 15 service users.

**Results:** Most service users highly appreciated the contact with the staff and the practical and emotional support. Persistent involvement, availability and humanity, and respect for autonomy were distinguished as core values in the relationship with the staff. Most service users experienced improvement in time and attributed this to intrapersonal changes and/or less stress in life.

**Conclusions:** From the perspective of service users with MID/BIF, FACT appears to have an added value.

## KEYWORDS

(flexible) assertive community treatment, borderline intellectual functioning, grounded theory approach, mild intellectual disability, qualitative research, service users' experiences

## 1 | INTRODUCTION

Assertive Community Treatment (ACT) is a relatively new type of care for people with mild intellectual disability (MID) or borderline intellectual functioning (BIF) and additional problems, such as mental health problems, addiction or challenging behaviour. ACT has its origin in mental health care and was developed in the 1970s in the United States for people with severe mental illness, combined with problems in important domains in life (e.g. housing, finances, work, social functioning; Stein & Test, 1980). In short, ACT teams focus on individuals

who cannot sufficiently be reached by and treated in regular inpatient or outpatient mental healthcare facilities, because of the complexity and plurality of their problems and/or their lack of motivation for professional help. ACT was developed to "bind" these people again by assertive outreach and by supporting them in their direct needs and in their own environment. ACT teams provide ambulant, intensive, comprehensive, multidisciplinary and long-term treatment and care to improve clients' functioning and participation in society and to prevent or shorten hospital admissions (see, e.g., Bond, Drake, Mueser, & Latimer, 2001; Stein & Santos, 1998; Van Vugt et al., 2011).

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2020 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd

In the Netherlands, an adaptation of the original ACT model was developed: Flexible ACT (FACT). FACT combines highly intensive multidisciplinary treatment (ACT) for unstable clients at risk of relapse with moderate intensive care for the more stabilized ones (Van Veldhuizen, 2007). In less intensive phases, clients are visited on average once a week. When symptoms aggravate or life events occur, the treatment is “scaled-up” to the ACT level. With more than 400 FACT teams, FACT has become the standard for organizing care for people with severe mental illness in the Netherlands. A second important development was the extension of the principles of the (F)ACT<sup>1</sup> model to other groups of people with special needs, including individuals with MID/BIF and mental health problems or challenging behaviour (Authors, 2018). As in mental health care, (F)ACT MID/BIF teams comprise several disciplines (psychiatrist, behavioural therapist, social workers, psychiatric nurses, addiction specialists) and provide a wide range of treatment and supporting interventions with respect to daily activities, housing, finances and administration, work and day structure. The teams offer long-term care and stay in touch in case of admission in a psychiatric hospital or detention.

Although the research base of (F)ACT for people with intellectual disabilities is small and the comparability of studies on this subject is limited, there are some indications that this type of care may be of value for this target group. Several authors reported positive outcomes, in terms of a reduction in behavioural problems and/or a decrease in admissions (Coelho, Kelley, & Deatsman-Kelly, 1993; Douglass & Hurtado, 2013; Hassiotis et al., 2001; King et al., 2009; Meisler et al., 2000; Van Minnen, Hoogduin, & Broekman, 1997).<sup>2</sup> Recently, we performed a longitudinal study and found that in general, clients of FACT MID/BIF teams showed improvement on several outcome measures, including social and psychological functioning, admissions in psychiatric hospitals and the level of social disturbance (Neijmeijer, Korzilius, Kroon, Nijman, Didden, 2019). Assuming that these results could be (partly) attributed to the efforts of (F)ACT, an important question is which ingredients of the (F)ACT model have contributed to the improvements. Since (F)ACT can be characterized as a “complex intervention” containing several interacting components (Craig et al., 2008), this is hard to investigate. Among researchers, the idea is widespread that complex interventions can only be investigated properly by using different research sources (Craig et al., 2008) and by combining quantitative and qualitative research methods (e.g. Chaplin, 2009; Oliver et al., 2005). Qualitative research can give insight into the active ingredients of the intervention, the relationship between professional and client and the required treatment of individuals with MID/BIF (e.g. Hemmings, 2008).

From research among service users with severe mental illness and, in general, average intelligence, it is known that they appear to benefit the most from non-specific elements of ACT, that is the

relationship with the staff (Krupa et al., 2005; McGrew, Wilson, & Bond, 1996). Also, research suggests that the relationship is facilitated by structural aspects of the ACT model, such as continuity, long-term involvement, flexibility and accessibility (Krupa et al., 2005). However, we cannot assume that the results of these studies can be applied automatically to service users with MID/BIF as well. Research on personal experiences of service users with an intellectual disability is scarce anyhow. Beail and Williams (2014) found that qualitative studies, published in three major intellectual disability journals over a decade, in which the participants were people with intellectual disabilities, represented only a minority of all published papers. Griffith, Hutchinson, and Hastings (2013) came to a similar conclusion. Remarkably, the themes that emerged from their research had mainly to do with “imbalance of power,” that is the application of restrictive interventions and the impersonal and authoritarian attitude of the staff, and the effect on challenging behaviour. Further, the vast majority of participants in these studies (97%) were residing in a secure or supported residential placement and only one of the studies focussed on people with “mild learning disabilities.”

The current qualitative study focusses on the experiences of service users with MID/BIF and mental health problems or challenging behaviour with FACT. The aim of the study was to explore how they value the treatment, how they value their (changes in) functioning and well-being, and which factors are perceived as supportive.

## 2 | METHOD

### 2.1 | Study design

Since little is known about the experiences of service users with MID/BIF with (F)ACT, this study has an explorative character. An inductive grounded theory approach (Glaser & Strauss, 1967) is most common for studies with an explorative character. To interpret and discuss the results of our study, we compare them with findings from literature and theories (triangulation or thick analysis)—which is considered a realistic and useful strategy to increase the methodological quality of qualitative research (Van Staa & Evers, 2010). Ethical permission was given by the Ethics Committee of the Radboud University (ECSW2016-2811-451).

### 2.2 | Data collection

The current study used semi-structured interviews with service users of two FACT MID/BIF teams, located in the middle and the eastern part of the Netherlands. Both teams focussed on individuals with a high risk on offending behaviour. Both teams were certified by the Dutch Centre of Certification of ACT and FACT teams, meaning that they had implemented the FACT model adequately.

<sup>1</sup>In this paper, we use the term “(F)ACT” as a collective name for both ACT and FACT.

<sup>2</sup>For a more detailed overview of the international state of the art of (F)ACT for people with (M)ID/BIF, see (Neijmeijer, Didden, Nijman & Kroon 2018).

The teams were informed about the study and the procedure by the first author and were asked to deliver an overview list of service users who met the following inclusion criteria: meeting the general FACT criteria (long-term history in (mental) health care; severe and enduring mental health problems and/or challenging behaviour; severe problems on different areas of life); having a determined MID (IQ 50–70) or BIF (IQ 70–85); enrolled in FACT for at least 9 months. The last criterion was included so that participants could form a balanced opinion. Service users who were detained or admitted in a psychiatric hospital were excluded, as well as those who were mentally unstable.

From the service users who met the criteria, a purposive sampling strategy was applied to ensure variability in experiences among the participants (Patton, 1990). Purposeful sampling is widely used in qualitative research for the identification and selection of information-rich cases related to the phenomenon of interest. In our study, maximum variation sampling was used to reveal different perspectives and experiences. In this method, participants are chosen purposefully based on variation on dimensions of interest—in our case: gender, receiving voluntary/involuntary treatment, main diagnosis and IQ level. This is done to ensure the presence of maximum variability within the primary data, but simultaneously, to identify important common patterns that cut across variations. The selected service users were informed, both orally and by letter, by their case manager or therapist (psychologist or behavioural specialist) and were asked to participate in the interviews and to sign an informed consent form. Service users could indicate the location of the interview (at service users' home or residence, at the office of the FACT team or elsewhere) and whether they wanted to be accompanied by a family member, close friend or a FACT team member.

A topic guide was constructed for the semi-structured interviews. Questions that were asked to elicit experiences were, for example, "What has the FACT team done for you thus far?", "Do they listen to you?", "Has the FACT team ever done something or said something that you felt not happy or even angry about?", "How do professionals have to treat you? And how not?".<sup>3</sup> To help the participants comparing their actual functioning and well-being with their condition at the start of the FACT treatment, we asked them to rate their state on a scale from 1 (extremely bad) to 10 (extremely good).

The interviews were conducted in tranches between February 2019 and July 2019 by the first author, assisted by a trained master student educational science. Six service users declined to participate, one was not reachable for the team, one was assessed as mentally unstable, and one had left the FACT team in the meantime. For them, other candidates were selected. To reduce the risk of bias by suggestive and leading questions, the first two interviews were, with permission of the participants, video-recorded and discussed afterwards with two experienced therapists. Also, the transcriptions of both interviews were discussed within an expert group, consisting of two psychologists with extensive

experience in FACT and three researchers with expertise in qualitative research.

Interviews were conducted with 15 participants (see below), lasted 30 to 75 min, and were audio-recorded and transcribed verbatim for coding purposes. As a token of gratitude for their participation, participants received a voucher. Afterwards, the audio recordings were deleted.

## 2.3 | Data analysis

An iterative process of data collection and analysis was used to develop a conceptual understanding of participants' experiences. First, open coding was used on all transcripts, resulting in more than 350 codes. Next, clustering of the codes by axial coding resulted in 14 categories, mainly corresponding to the interview topics (Table 1).

Next, selective coding led to four overarching themes, each with a number of subthemes (Table 2).

Throughout the analysis, memos were created to record reflexive notes, impressions and thoughts, which were regularly discussed between both interviewers. An audit trail was performed by the second author, by reading and assessing a selection of the original transcripts. Also, all steps in the process of coding and analyses were shared with the expert group.

Atlas.ti was used to support the organization and categorization of data. The COREQ criteria list for qualitative research (Tong, Sainsbury, & Craig, 2007) was used to guide the analysis and report.

## 2.4 | Participants

After 15 interviews had been reviewed, no new topics emerged from further coding and comparison and saturation was reached. Twelve

**TABLE 1** Main categories derived from the interviews

1.	History client
2.	Personal characteristics/attitude client
3.	Previous experiences with professional help
4.	Relational aspects of FACT
5.	Practical support of FACT
6.	Emotional support/therapy of FACT
7.	Organizational aspects of FACT
8.	Functioning at the start of FACT
9.	Actual functioning and well-being: positive
10.	Actual functioning and well-being: difficulties
11.	Helping factors
12.	Hindering factors
13.	Negative experiences with FACT
14.	Compulsory treatment

<sup>3</sup>A complete list of questions can be obtained from the first author.

**TABLE 2** Themes and subthemes derived from interviews

Themes	Subthemes
FACT treats me well	They don't let me down They are there for me - as a human They respect my autonomy
FACT meets my needs	They support me practically They give me emotional support and treatment
Overall I'm doing better now	I have grown stronger I have more structure and less stress in life
Tension fields	They don't do anything for me They are too restrictive

participants were male and three were female, aged between 22 and 60 years. The duration in FACT varied between one and seven years. There was a wide variety of DSM diagnoses, including addiction, personality disorder, schizophrenia, autism and ADHD. Ten participants lived independently (two of them with support from a regular intellectual disability facility), while four lived in supported residential facilities and one lived in a shelter. Eight participants had an actual judicial order (e.g. conditional sentence, conditional release from prison), four had an expired judicial order, and two had an actual civil measure (meaning that the service user had to undergo treatment within the framework of the Dutch Mental Health Act). IQ scores ranged between 59 and 80; eight participants had a MID (IQ between 50 and 70), seven functioned at borderline level (IQ between 70 and 85).

Remarkably, in none of the cases a family member attended the interview. Instead, four service users chose to be accompanied by their case managers during the interview. Because of their limited communication skills or their mental health condition, some participants found it difficult to express themselves—resulting in less rich research material. Nevertheless, we aimed to do justice as well as possible to the essence of the ideas and experiences of all participants (in the result section referred to with P1 to P15).

### 3 | RESULTS

Overall, all service users gave FACT favourable ratings. Expressed in a score between one and ten, three participants gave a seven, eight participants gave an eight or nine, while four valued FACT with even a ten.

#### 3.1 | Theme 1: FACT treats me well

Regardless of their condition or situation, all participants expressed their appreciation for the way they felt treated by the members of the FACT team. The question “What do you appreciate in the contact with FACT?” resulted in a long list of relational aspects. Closer analyses showed that most of these aspects referred to three core

values: persistent involvement, availability and humanity, and respect for autonomy.

##### 3.1.1 | Persistent involvement: They don't let me down

Several participants reported that they found it difficult to trust people. As an explanation, they referred to their negative experiences with professionals and (local) authorities in the past, or to the long-term impact of life events, such as mental illness, drug abuse or (violent) death of parents during childhood, sexual abuse or victimhood of violence. Life events can have a deep influence on the sense of safety:

*For me it is very important that professionals take me seriously. I think it is because of my past of sexual abuse. It is very important that I can trust people. In the past I wasn't taken seriously by people in my family*

(P6).

As an understandable reaction to adverse circumstances and life events, people might build a harness:

*In the beginning I didn't want professionals around me. I acted like it was all fine with me, but I hid the things that happened in my past*

(P10).

*In the beginning I was a troublesome guy, I say this honestly. I was angry and aggressive. Trusting caregivers was very hard for me, because I have experienced certain things in residential youth care institutions that I never had wanted to experience*

(P15).

Eventually, it was especially the combination of an unconditional, non-judging attitude and the persistent involvement of FACT that broke the barriers. As the following quotations illustrate, FACT stayed involved regardless of the circumstances and service users' behaviour and condition—even in case of admission in a (psychiatric) hospital or imprisonment:

*They supported me through thick and thin. I could become mad, I could react angry, you tell so, they have withstood everything with me*

(P6).

*I was admitted in a psychiatric hospital but no one looked after me or spoke with me. I just passed the time. Thankfully, FACT came to visit me. Actually, I had more contact with FACT than with the hospital staff*

(P2).

*I kept the door shut for them a couple of times. I just didn't want to see them because I wasn't in the mood or had a bad night or something. But they simply came back again. I didn't get rid of them that easy*

(P13).

All participants had been in treatment of FACT for quite a long time, a few even up to six or seven years. Because of FACT's unconditional support and their broad and open view with a focus on the competences and qualities of service users instead of their disabilities, they got the opportunity to change and prove themselves:

*My family guardian has a certain picture of me. She thinks I'm angry and aggressive and I can't take care for myself and for my children (...) But she refers to an assessment of nine or ten years ago (...) A. (systemic therapist) stands up for me at least. She says: that boy does well and when will you give him a chance?*

(P15).

### 3.1.2 | Availability and humanity: They are there for me, as a human

Another highly appreciated element—associated with unconditional—is the accessibility, the availability and the flexibility of FACT. Participants indicated that they can always rely on FACT:

*When I call them and they don't have time for me at that moment, they always call me back. Or when I want to change an appointment, I send a text message and it's fixed*

(P2).

*I can call or mail them every day*

(P10).

The interviews revealed that availability goes beyond professional availability and that availability as a human being is equally important. Generally, participants did not like it when professionals behave like professionals, that is hide behind their role as therapists and adopt an attitude of professional distance. Instead, sincere involvement requires authenticity, daring to show oneself as a human being, showing compassion and emotions:

*They are really involved with me. K. and M. (case managers) were present at the moment my children were taken away. I saw them crying (...) I had never seen that before, they were the first professionals who showed their emotions*

(P15).

*When I was sick, I had an infection, I showed it to W. (case manager) and he was in shock. I was really sick. I had to*

*go to hospital. They were all worried about me. They were engaged with me, for 100%*

(P12).

*When I was in jail, they looked after my pets, they brought me clothes. They gave me the feeling that they really cared about me*

(P4).

### 3.1.3 | Autonomy: They respect my personal space

Respect implies, among others, having sensitivity for someone's individuality and personal space. The interviews revealed that service users attach great importance to their autonomy and independence: they want to make their own choices and decisions.

*For me it is important that care givers just do what I need. Don't determine anything for me otherwise I will rock the boat*

(P1).

*They (care givers) must never say to me 'you have to'. Then I lose my head completely. The only thing I have to is to keep on breathing and to wipe my ass*

(P5).

Some participants referred to bad experiences in their past. The following statements were done by participants who stayed in (forensic) residential institutions previously.

*In the TBS (forensic psychiatric institution) the staff determined everything for me. I don't like that. I find it irritating when they push me and give me the feeling that I have to act in a certain way*

(P1).

*My heaviest period was when I stayed in residential youth care. I was an aggressive boy, I was put in isolation ... they didn't know how to handle me, I was hold down and forced to the ground*

(P12).

Respecting someone's boundaries also implies taking into account service user's emotional condition, psychological capacities and coping style. Several participants indicated that keeping some control over the intensity of the treatment process was very important for them:

*Meanwhile I know when treatment suits me or not. FACT feels good. One moment, I talk with W. (case manager) about things that happened in the past. Another, I talk*



*about football (...) Things must not go too fast for me. Otherwise it turns out bad*

(P12).

Generally, participants believed that FACT meets their needs regarding autonomy and self-determination sufficiently—even if there are disagreements at times:

*First they said to me I had to take medication. But when I told them I didn't want to, they didn't push me, they didn't force me to take it. However, they did inform me about the risks*

(P10).

*In the beginning, there were many things of which I thought 'mind your own business'. But now, I take things differently and at least I think about the things they say. And sometimes I say yes and sometimes I say no. From time to time they try to push through but when I refuse, they withdraw*

(P2).

## 3.2 | Theme 2: FACT meets my needs

Besides the contact with the staff, participants appreciated the (daily) support they received from FACT. In reply to the question "What does FACT actually do for you?", most of the participants emphasized the practical support.

### 3.2.1 | Practical support

As the following quotations illustrate, participants received assistance with all kinds of activities, such as mail, administration and finances, contacts with (local) authorities (such as Tax Authorities and Employees Insurance Administration), day structure, work and housing—in general, much to their satisfaction.

*About six years ago, I was referred to FACT by the Salvation Army. I had lost everything, I lived on the street, slept in a squat. I was in a bad shape. And then they helped me to get everything on track again. I didn't have an identity document anymore. I also had lost my house, my stuff, everything*

(P14).

*Right now I have troubles with my disability benefits, because I am going to marry and my girl friend has moved in with me. They solve this for me, it's going to be all right. And I have problems with the internet and tv, although I pay for it.*

*I've had a technician at home, but the problem is still there. And then I have to call 40 times and I'm being transferred all the time and eventually I break the line and then I have to start all over again. And they can arrange that for me, I think they have been trained or something*

(P14).

*Recently I had to go to the doctor because of sleeping problems. D. (case manager) went with me. She brought me with her car, so I didn't have to arrange my own transport*

(P13).

### 3.2.2 | They give me emotional support and treatment

Besides the practical support, participants mentioned the emotional support of the FACT team, ranging from daily counselling and monitoring to anger management, trauma treatment and system therapy.

*For me it's difficult to deal with stress and emotional events. Last week I didn't feel well. When they came, I have discussed this with them. I have told them everything what bothered me and what's going on inside me*

(P15).

*I have had EMDR and that was very intense. All kind of things happened in my head, my past came up again and I saw images and flashes (...) EMDR is really an intense therapy, it tackles the problem in your brain*

(P6).

*A (systemic therapist) went to my parents when I was in jail for a long time. That was really nice, my mother told me how glad she was to talk with A. And A. gave relation therapy to my partner and me. Nowadays, the relationship is going just fine and we go along with each other well, so we don't need the therapy anymore*

(P9).

Some participants received pharmacotherapy from FACT as well:

*R. (psychiatrist) doesn't come often, but if he comes he talks with me. For example, when I had a relapse. And then he discusses with me why the relapse has happened. And he discusses the use of medication, recently we did*

(P4).

### 3.3 | Theme 3: Overall, I'm doing better now

#### 3.3.1 | I have grown stronger

When asked "How are you doing now, compared to when you started FACT?", most participants perceived improvement over time. Several of them indicated that they are better able to cope with stress and stressful situations, to express and manage their emotions and that they are more in harmony with themselves and their environment. They have gained insight into their problems and disabilities and have less problems with professionals and (local) authorities.

*I was referred by the probation. I drank a lot, I didn't give a shit about anything. I had problems with local authorities. But the last two years, I have made progress. I've learned to seek help. When I have troubles, I text K. (case manager) or S. (psychologist) and tell them that I need to talk for a moment*

(P8).

*I have learned to trust people. I can handle my emotions better now. I am less angry and aggressive. I can open up myself much better. The fact that I have lost a lot remains difficult for me. But it's a matter of learning to accept and to go on*

(P15).

*I'm doing better now. I don't relapse anymore, I don't become psychic anymore. In the past, when I was busy in my head, I ran away. Now I don't do that anymore*

(P11).

*In the past I leaped from one thing to another, and now I first think before I do something and that helps me*

(P2).

However, as the following quotations indicate, the way to recovery is hard and often not continuous:

*I still find it difficult to deal with stress and tensions. That can bring out certain behaviour in me, you know, old behaviour. And that's not social, it's asocial. When I think that people don't take me seriously or that I'm treated unfair. I can't deal with that. I have learned things in my life in a hard way. I have to keep on doing my best since the consequences can be major*

(P15).

*I'm doing fine. I drink beer now but that's because I have a headache. I know why, yesterday I boozed, I drank beer and wine (...) Usually I have structure in drinking. I stand*

*up and I drink coffee. The best is to stand up early and drink after 5 p.m.*

(P14).

*In the summer I am more stable, in the winter I am more depressed. That's because of my illness, sometimes I peak and then I go whoop*

(P2).

*I'm doing quite well. In fact I don't need support at all. Except when it's going bad, when I have voices in my head. Then I neglect myself and my environment, I look tv and I don't want to talk with anyone*

(P1).

When asked, in case of amelioration, "How could these changes happen?" several participants referred to intrapersonal changes and better coping skills—largely as a result of their treatment in FACT. For some participants, understanding of "what's wrong with them" helped them to accept their intellectual and/or mental health limitations. Although several service users had been treated in (mental) health care before, a clear diagnosis was not always made, and therefore, adequate treatment has been left out for a long time:

*In the past I didn't know what was wrong with me. In residential care I was very aggressive, they couldn't handle me at all. Five years ago, I was tested in FACT. I have a learning disorder and a bipolar disorder. Maybe I have had it always, but I didn't know it*

(P2).

Some participants attributed the results not so much on what they had learned in FACT, but rather on an autonomous process, a kind of mind shift—motivated by intrinsic/pull factors (life goals) or extrinsic/push factors (not wanting to go in jail anymore).

*I took the decision that I didn't want to go to jail anymore. I turned the switch. I don't go to the city anymore to steal, I have really forsworn stealing. You're becoming older and then you just don't want that anymore. I don't want to look behind all the time and to steal for drugs*

(P13).

*When you are young, you are doing silly things, like jumping from a bridge, fighting and driving when drunk. But when my little daughter was born, my brother told me: Stop with doing that, you want to see grow up your daughter don't you? Now I live more careful*

(P14).



### 3.3.2 | I have more structure and less stress in life

Besides personal growth, several participants mentioned that they experience more rest and less stress in life because of changes and improvements in their environment, particularly with respect to housing, finances and administration. Also, having a day structure and having distraction by daily activities were mentioned several times as an important source of support.

*I have chosen to stay under guardianship because when I have to do everything by myself, things turn wrong. It costs something, but everything is arranged and I don't come in problems anymore*

(P8).

*Work is an important distraction for me, otherwise I sit still the whole day, and I can't handle that. I have to stay active, go outside, into the nature. I walk a lot. In the past I went to the city. But now I know that's not good for me, so I avoid the city*

(P13).

*In the past I have been in jail many times. I had a lot of outstanding fines because I was driving under influence and so on. And I had many debts. But now I have a bike instead of car and my administrator handles my mail. And now I am penalty-free*

(P14).

## 3.4 | Theme 4: Tension fields

Although the majority of the participants valued FACT positively, there were some critical remarks as well.

### 3.4.1 | They don't do anything for me

Two service users (P1 and P5) were considerably disappointed about the practical help from FACT. Both men were frustrated since FACT had not succeeded in what they needed the most: another home. One of them said:

*They don't do anything for me. Yes, they come along for a talk. But what can they do? They can't do anything. I am lost already. Nothing happens, they don't change my situation. They are just like the probation: they talk to me and then they go again*

(P5).

However, despite their dissatisfaction about what FACT has actually done for them, both participants were rather positive about the relational aspects of FACT:

*I've known them for quite a while now and they haven't done anything for me, but I don't dislike them*

(P5).

*They still haven't arranged my housing. And they keep moaning about my past. But the contact is reasonably well. At least, they don't control me 24 hours a day*

(P1).

### 3.4.2 | They are too restrictive

While, as reported above, most participants believed that FACT respected their autonomy sufficiently, some of them reported restrictive practices as well. It should be noted that participants differed in their perception of restrictive or authoritarian. For instance, some participants indicated to benefit from a clear and directive approach, while others warned that they cannot stand it when caregivers are too compelling:

*When K. (case manager) sees that I'm not acting good, he calls me to account. That's okay. Sometimes I need someone to kick my ass. It doesn't help me when someone is just kind to me. Sometimes I need some pressure*

(P8).

*L. (case manager) is a woman that...she isn't wrong or bad or something...but she is more intrusive, in a kind of 'you must, I want to see this, I want to see that' and then I think: listen, if you tell me what to do, then I show you the door. I don't have to do anything*

(P15).

Sometimes, the feeling of restriction was related to their judicial status:

*It's not that I have the feeling that they oblige me or something. It's more that I think I have had probation supervision for so long now, why can't they stop it? My legal measure ends in 2021 and as long I'm under supervision, I receive treatment from FACT. And sometimes I'm just through with it*

(P9).

*FACT visits me twice a week. I believe that's too much actually. Sometimes I need more rest because I don't feel very well. But I can't cancel them too often, because I'm bound to receive treatment*

(P8).

Also, medication use can be experienced as a breach of someone's autonomy:

*I want to reduce my medication, but they say that's not good for me. Sometimes we have conflicts on this subject, while I always have done what they told me. Preferably I don't want medication at all*

(P3).

## 4 | DISCUSSION

### 4.1 | Reflection on the results

In this paper, we presented the results of a qualitative study on the experiences of service users with MID/BIF and mental health problems or challenging behaviour with FACT. The aim of the study was to explore how service users valued the treatment of FACT, how they valued the results of FACT, in terms of well-being and functioning, and which factors they perceived as supportive or helping. With respect to the overall valuation of FACT, the majority of participants were very satisfied. The positive valuation seemed to be connected with two factors: the relational aspects and the practical and emotional support they received. With respect to the relational aspects, service users appreciated especially the unconditional and long-term involvement of the team members (continuity of care), their availability, their sincere interest and humanity, and their respect for the autonomy and freedom of choice. For several participants, these positive experiences contrasted sharply with their previous experiences in mental health care, residential youth care and judicial institutions. With respect to the results of the treatment, most participants experienced improvement over time and indicated that they were better able to cope with stress and stressful situations and to express and manage their emotions. To what extent these improvements could be attributed to the interventions of the FACT team was difficult to determine. While some participants made a clear link to what they learned in FACT, others spoke of an intrapersonal change that was motivated by intrinsic or extrinsic factors.

The finding that all participants had an overall positive valuation of FACT is remarkable. Even those who obviously struggled with complicated problems in life mostly appreciated the involvement of FACT. Also, receiving compulsory treatment was not related directly to the valuation of FACT. Indeed, several service users indicated that FACT helped them to break the vicious circle of negative functioning, trouble with local authorities and criminality and admitted that they needed FACT as a precaution and to stay on track. Apparently, FACT is able to build up a trusting bond with individuals with complex and multiple problems, often with a burdened past and a criminal history, who have found traditional services unable to meet their needs. It is noteworthy that our findings contrast with the results of previous qualitative studies on the experiences of service users with intellectual disabilities—which were mostly performed in the context of residential settings (Griffith et al., 2013). Other than in many residential settings where individuals with intellectual disabilities experience accumulative stressors, causing continued challenging behaviour,

FACT service users do not seem to be affected (that much) by the “iatrogenic harm” of clinical institutions. Instead, they emphasize especially their positive experiences with FACT.

In this respect, a parallel may be drawn with the results of studies on experiences of service users suffering from severe mental illness with ACT. Overall, both groups of service users had positive experiences with ACT, and both groups referred to the relational as well as the content elements if asked for the supportive factors. The fact that caregivers “just” do what they need the most and “just” treat them respectfully might be considered as obvious, but is often not in line with service users' experiences with (mental) health care in the past. For example, Stuen, Rugkåsa, Landheim, and Wynn (2015) performed in-depth interviews with 15 patients that received involuntary treatment by ACT and concluded that: “Although experiencing difficulties and tensions, many participants described the ACT team as a different mental health arena from what they had known before, with another frame of interaction. Despite being legally compelled to receive treatment, many participants talked about how the ACT teams focused on addressing unmet needs, the management of future crisis, and finding solutions to daily life problems” (p.11).

Although the majority of the participants valued FACT positively, it is important to reflect on the critical remarks as well. Some participants felt frustrated because FACT could not arrange adequate housing for them, while others struggled with, for example, medication use. Tensions and conflicting interests were found in studies among service users of regular ACT as well. For example, McGrew, Wilson & Bond (2002) performed a study among clients on the negative aspects of ACT and found that intrusiveness, the confining nature of ACT, overemphasis on the use of medication, low frequency of contacts and limited availability of staff were perceived as the most important drawbacks. The delicate balance between professional responsibility and clients' self-responsibility, or between social control and building up a therapeutic relationship, is an ethical dilemma which is considered as inherent to ACT (Watts & Priebe, 2002). On the basis of a qualitative research on the experiences of clients with coercive techniques in ACT, Appelbaum and Le Melle (2008) recommend to keep on investing in the relationship with clients by caring, listening and encouraging, since this can be seen as the most important working ingredient of ACT.

### 4.2 | Strengths and limitations

In qualitative research, the researcher is a central figure who influences, if not actively constructs, the collection, selection and interpretation of data (Finlay, 2002). In the current study, the main researcher had extensive knowledge and experience in the area of (F)ACT MID/BIF, both as a researcher and as a trainer, coach and auditor. To reduce the risk of biased interpretations, we embedded a number of precautions in our study design, such as logbooks, frequent exchange of experiences and ideas between both interviewers, an audit trail performed by the second author and critical conversations with an expert group containing both professional and

methodological expertise. In our judgement, these measures have led to a balanced description of the results which reflect both the positive and the negative experiences of service users with FACT.

To what extent the findings are representative for the research population (i.e. service users of FACT MID/BIF teams) is hard to determine. The fact that most of the participants underwent the FACT treatment involuntary because of a judicial order may limit the transferability of the results. Also, nine service users declined to participate in the interviews. Although avoidant and reluctant behaviour is common in this population and was found within the participant group as well, it is possible that the non-participants had less positive experiences compared with the participants. Moreover, most of the participants have been in treatment of FACT for quite a long time. It is possible that service users who were admitted more recently have different or less positive experiences, because they might experience more problems and suffering. However, our findings show that the valuation of FACT is not necessarily related to the current level of well-being of the service users. Further, our findings are congruent with the outcomes of earlier performed studies on the experiences of service users of regular ACT (Krupa et al., 2005; McGrew et al., 1996), as well as with the recommendations of Griffith et al. (2013) regarding the preferred attitude and treatment of people with intellectual disabilities and challenging behaviour.

Four service users chose to be accompanied by their case managers during the interviews. Since people with MID/BIF may be easily influenced, this could have distorted the findings. However, it is characteristic for the caseload of FACT MID/BIF teams as well that many of them live an isolated life and do not have caring relatives or close friends. For these people, their professional carers form their social network and are considered as relatives or friends—which was also reflected by the interviews. As far as we can assess, the presence of case managers at the interviews did not influence the participants in their answers. Indeed, the participants who were accompanied by their case manager did not mince words if they had critical remarks on FACT. Also, the presence of a case manager was a necessary support for several service users to participate. The possible influence of the case manager on the valuation of the participants was explicitly brought up in the interviews, and all participants denied that this was the case.

This study was aimed at service users' experiences, not in finding the truth. During the evaluation of the pilot interviews, it appeared that service users did not always give a correct representation of how things went in the past and the support they received by FACT. Sometimes, participants forgot things to tell or could not make clear in which sequence events had occurred, for what reasons they were referred to FACT or to argue their opinions. Also, some participants tended to overestimate themselves, at the expense of the efforts of FACT. It is known that interviewing persons with intellectual disabilities can pose problems in terms of reliability of data (see, e.g., Finlay & Lyons, 2001). To optimize the quality of data collection, sentence structures were simplified, questions were adjusted, and answers were summarized

and checked. However, what counts for people in general goes for people with MID/BIF as well; they reason, feel and interpret from their own perspectives. Personality, self-insight, level of understanding and experiences in the past colour their perceptions. For a more complete insight into the working ingredients of FACT MID/BIF, it might be useful to extend the research activities to FACT team members as well.

## 5 | CONCLUSION

From service user's perspective, FACT appears to have an added value and seems to be able to build up a trusting bond with individuals with MID/BIF and complex and multiple problems, often with a burdened past and a criminal history. An important area of attention for FACT MID/BIF teams is to achieve an optimal balance between professional responsibility, control and structure on the one hand and client's autonomy, independence and freedom on the other.

## ACKNOWLEDGMENTS

The authors would like to thank Carolien Knipping, Jesse Roest, Otto Has and Jan Enserink for their contribution to the research and this paper.

## CONFLICT OF INTEREST

The authors report no conflict of interests.

## ORCID

Laura Neijmeijer  <https://orcid.org/0000-0001-8262-4893>

## REFERENCES

- Appelbaum, P. S., & Le Melle, S. (2008). Techniques used by assertive community treatment (ACT) teams to encourage adherence: Patient and staff perceptions. *Community Mental Health Journal*, 44(6), 459–464.
- Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27(2), 85–96.
- Bond, G. R., Drake, R. E., Mueser, K. T., & Latimer, E. (2001). Assertive community treatment for people with severe mental illness. *Disease Management and Health Outcomes*, 9(3), 141–159.
- Chaplin, R. (2009). Annotation: New research into general psychiatric services for adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, 53, 189–199. <https://doi.org/10.1111/j.1365-2788.2008.01143.x>
- Coelho, R. J., Kelley, P. S., & Deatsman-Kelly, C. (1993). An experimental investigation of an innovative community treatment model for persons with a dual diagnosis (DD/MI). *Journal of Rehabilitation*, 59(2), 37.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: The new Medical Research Council guidance. *British Medical Journal*, 337, a1655. <https://doi.org/10.1136/bmj.a1655>
- Douglass, E. L., & Hurtado, B. (2013). Establishing and evaluating an assertive outreach team. *Learning Disability Practice*, 16(9), 30–34.

- Finlay, L. (2002). Negotiating a swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2, 209–230.
- Finlay, W. M. L., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13(3), 319–335. <https://doi.org/10.1037/1040-3590.13.3.319>
- Glaser, B., & Strauss, A. (1967). Grounded theory: The discovery of grounded theory. *Sociology the Journal of the British Sociological Association*, 12(1), 27–49.
- Griffith, G. M., Hutchinson, L., & Hastings, R. P. (2013). "I'm not a patient, I'm a person: The experiences of individuals with intellectual disabilities and challenging behaviour – a thematic synthesis of qualitative studies. *Clinical Psychology Science and Practice*, 20(4), 469–488.
- Hassiotis, A., Ukoumunne, O. C., Byford, S., Tyrer, P., Harvey, K., Piachaud, J., ... Fraser, J. (2001). Intellectual functioning and outcome of patients with severe psychotic illness randomised to intensive case management. *British Journal of Psychiatry*, 178(2), 166–171.
- Hemmings, C. P. (2008). Community services for people with intellectual disabilities and mental health problems. *Current Opinion in Psychiatry*, 21, 459–462.
- King, R., Jordan, A., Mazurek, E., Earle, K., Earle, E., & Runham, A. (2009). Assertive community treatment-dually diagnosed: the hyphen was the easy part. *Mental Health Aspects of Developmental Disabilities*, 12(1), 1–7.
- Krupa, T., Eastabrook, S., Hern, L., Lee, D., North, R., Percy, K., ... Wing, G. (2005). How do people who receive assertive community treatment experience this service? *Psychiatric Rehabilitation Journal*, 29(1), 18–24.
- McGrew, J. H., Wilson, R. G., & Bond, G. R. (1996). Service user perspectives on helpful ingredients of assertive community treatment. *Psychiatric Rehabilitation Journal*, 19(3), 13.
- McGrew, J. H., Wilson, R. G., & Bond, G. R. (2002). An exploratory study of what clients like least about assertive community treatment. *Psychiatric Services*, 53(6), 761–763.
- Meisler, N., McKay, C. D., Gold, P. B., Schales-Elkins, P., Benasutti, R., & Santos, A. B. (2000). Using principles of ACT to integrate community care for people with mental retardation and mental illness. *Journal of Psychiatric Practice*, 6(2), 77–83.
- Neijmeijer, L. J., Didden, R., Nijman, H. L. I., & Kroon, H. (2018). Assertive community treatment for people with mild intellectual disability or borderline intellectual functioning and mental health problems or challenging behavior: State of the art and implementation in the Netherlands. *Journal of Policy and Practice in Intellectual Disabilities*, 15(4), 329–342.
- Neijmeijer, L. J., Korzilius, H. P. L. M., Kroon, H., Nijman, H. L. I., & Didden, R. (2019). Flexible assertive community treatment for individuals with a mild intellectual disability or borderline intellectual functioning: results of a longitudinal study in the Netherlands. *Journal of Intellectual Disability Research*, 63(8), 1015–1022.
- Oliver, P. C., Piachaud, J., Tyrer, P., Regan, A., Dack, M., Alexander, R., ... Rao, B. (2005). Randomized controlled trial of assertive community treatment in intellectual disability: The TACTILD study. *Journal of Intellectual Disability Research*, 49, 507–515.
- Patton, M. (1990). Purposeful sampling. *Qualitative Evaluation and Research Methods*, 2, 169–186.
- Stein, L. I., & Santos, A. B. (1998). Assertive community treatment of persons with severe mental illness. New York, NY: W.W. Norton.
- Stein, L. I., & Test, M. A. (1980). Alternative to mental hospital treatment: Conceptual model, treatment program, and clinical evaluation. *Archives of General Psychiatry*, 37, 392–397.
- Stuen, H. K., Rugkåsa, J., Landheim, A., & Wynn, R. (2015). Increased influence and collaboration: A qualitative study of patients' experiences of community treatment orders within an assertive community treatment setting. *BMC Health Services Research*, 15(1), 1–13. <https://doi.org/10.1186/s12913-015-1083-x>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Van Minnen, A., Hoogduin, C. A. L., & Broekman, T. G. (1997). Hospital vs. outreach treatment of patients with mental retardation and psychiatric disorders: A controlled study. *Acta Psychiatrica Scandinavica*, 95(6), 515–522.
- Van Staa, A., & Evers, J. (2010). 'Thick analysis': Strategie om de kwaliteit van kwalitatieve data-analyse te verhogen. [Thick analysis: Strategy to improve the quality of qualitative data analysis]. *Tijdschrift Voor Kwalitatief Onderzoek in Nederland*, 43(1), 5–12.
- Van Veldhuizen, J. R. (2007). FACT: A Dutch version of ACT. *Community Mental Health Journal*, 43, 421–433. <https://doi.org/10.1007/s10597-007-9089-4>
- van Vugt, M. D., Kroon, H., Delespaul, P. A. E. G., Dreef, F. G., Nugter, A., Roosenschoon, B.-J., ... Mulder, C. L. (2011). Assertive community treatment in the Netherlands: outcome and model fidelity. *The Canadian Journal of Psychiatry*, 56(3), 154–160. <https://doi.org/10.1177/070674371105600305>
- Watts, J., & Priebe, S. (2002). A phenomenological account of users' experiences of assertive community treatment. *Bioethics*, 16(5), 439–454.

**How to cite this article:** Neijmeijer L, Kuiper C, Kroon H, Didden R. Experiences of service users with a mild intellectual disability or borderline intellectual functioning with Flexible Assertive Community Treatment: A qualitative study. *J Appl Res Intellect Disabil*. 2020;33:1005–1015. <https://doi.org/10.1111/jar.12723>